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TITLE: Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer

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<b>14. ABSTRACT</b> Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results on their own. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance. The FORCE website ( <a href="http://www.facingourrisk.org">www.facingourrisk.org</a> ) serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and the forms that competent coping takes. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer. To date, we have combined quantitative and qualitative analyses to identify and examine one of the most frequently discussed topics on the message boards; decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Other papers in progress include the decision to undergo prophylactic mastectomy and subsequent decisions surrounding reconstruction, the lived experience of prophylactic mastectomy, and sense of self and renegotiation of identity following prophylactic mastectomy.					
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## **Introduction**

Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results on their own.

They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance.

Facing Our Risk of Cancer Empowered (FORCE) is a nonprofit organization and associated website ([www.facingourrisk.org](http://www.facingourrisk.org)) devoted exclusively to the community of women at risk for HBOC. FORCE serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project involves evaluation of the activity and content of the FORCE website.

All data is collected online and is completely anonymous. The project samples message board discussions for emergent issues and themes, recurring problems, and strategies for successful coping. Procedures include formal content analysis of archived threads and specific queries posed to a representative consumer board of women participating in FORCE activities. Additional analyses focus on the social structure of the FORCE community, how it is used by members of HBOC families, and how it reflects the unmet needs with respect to the medical system.

This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and characterize forms of competent coping. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer.

## **Body**

This project was approved for data collection on May 17, 2004. Since that time we have downloaded more than 8,600 separate threads appearing on the FORCE message boards between August 1999 and September 2004, formatted and categorized the resulting text documents for compatibility with our analytic software program, QSR-N-VIVO, and entered and coded significant portions of the data to facilitate searches and detailed analyses.

Key members of the research team attended training sessions to become proficient in N-VIVO data management and analyses. In addition, we were fortunate to be able to forge a collaboration with a senior qualitative sociologist who specializes in women's health and genetics—specifically issues related to HBOC. The combined efforts of our study investigators with expertise in qualitative and/or quantitative methodology facilitated detailed analyses of textual data with a degree of precision often lacking in purely qualitative research.

Initial quantitative analyses identified the themes of message board threads with the highest frequency and greatest continuity of activity. To date, we have combined quantitative and

qualitative analyses to identify and examine the most frequently discussed topics on the message boards, which are as follows:

1) The first area of investigation is decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Results of these analyses were presented at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer* and were well received.. In November 2005, the related manuscript, entitled “Peer-Support in Coping with Medical Uncertainty: Discussion of Oophorectomy and Hormone Replacement Therapy on a Web-Based Message Board” was submitted to *Social Science & Medicine* but was not accepted, with the editor of this international journal indicating that dilemma faced by the women of F.O.R.C.E was particular to the American context where women lack support of medical personnel for decision-making regarding HRT after PO (a key point of the manuscript). The manuscript is currently under review at *Psycho-Oncology*. The abstract is as follows:

“The FORCE (Facing Our Risk of Cancer Empowered) website is devoted to women at risk for hereditary breast and ovarian cancers (HBOC). To understand the unique health concerns and emotional support needs of these women, we examined threads on the /FORCE/ archived message boards with relevance to the broader HBOC community. We report on a thread discussing the controversial decision to use hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). We used a qualitative research inductive process involving close reading, coding and identification of recurrent patterns, relationships and processes in the data. Twenty-nine women posted 177 messages over 7 months. Two main groups of women posted: 1) Women who were BRCA+, had completed PO, and were debating or adjusting their HRT options in terms of optimizing both quality and quantity of life. 2) Women who were BRCA+, were contemplating PO, but wanted to better understand the potential physical and psychological consequences of surgical menopause before deciding. Frustrated by physicians’ lack of knowledge and contradictory media articles about the long-term consequences of HRT in BRCA+ women, they sought resources, emotional support and specific experiential knowledge from each other and generated a unique sense of community and a high level of trust.”

2) The second issue under investigation involved the decision to undergo prophylactic mastectomy (PM) and subsequent decisions concerning breast reconstruction. An oral presentation, *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*, was delivered at the 2006 *Society of Behavioral Medicine* annual meeting. The presentation discussed bilateral prophylactic mastectomy (BPM) as a preventive strategy available to women with BRCA mutations. Themes in the content of women’s communications on the FORCE message board were examined, to identify psychosocial and physical concerns surrounding the decision to undergo prophylactic mastectomy with or without reconstruction, the processes involved in such decisionmaking, and the impact of their decisions on quality of life. Analyses of 203 messages were conducted using QSR N-Vivo, a qualitative software program. Findings suggest that women grieve during the decision process, feel confident in their choices, feel relieved after surgery, and feel empowered by the process of taking control of their bodies and future health.

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3) The third issue under investigation is the lived experience of prophylactic mastectomy and related issues e.g., surveillance and reconstruction. Therefore, we are investigating the subject matter of these messages and the women's purposes for writing about these issues with an emphasis on the subsequent socioemotional and practical details that went unaddressed in medical consultations leading up to the decision to undergo PM. . We also are interested in learning more about how the women used the message board with these gaps in their preparedness, what sort of information and support they received from the message board and how they "gave back" to the message board regarding the issues surrounding prophylactic mastectomy. Such reciprocity in social support seems to be an important theme in these messages. To conduct our research, we are analyzing threads about prophylactic mastectomies on the archived message boards during the period June 2000 – March 2004. We have finished a preliminary analysis involving the 7 women would made the most consistent contributions to the threads and are in the process of analyzing the postings of an additional 16. On the basis of the preliminary findings, we have begun writing a paper on the lived experience of decision-making these women go through, starting from the time they learned about HBOC and the possible morbidity and mortality associated with having a BRCA1/2 mutation. A working title for this article is: "The PM journey on the FORCE Website". We will cover messages dealing with: influence of family history, genetic testing, pre-PM worries, pre-PM decisions, looking for help in making a decision, insurance coverage difficulties, deciding on surveillance instead of PM, day before PM thoughts and experiences, post-PM thoughts and experiences, trouble with implants, and giving information, opinions and advice. This manuscript should be ready for submission in Fall 2006 and is intended to lay the groundwork for more patient-oriented content in the medical consultations leading up to prophylactic surgery..

4) The final topic is a psycho-social interpretation of problems women face post-PM with or without reconstruction, based on the works of Goffman and Charmaz regarding risks of disclosure, possible social stigma or rejection, sense of self and renegotiation of identity. We report on the women's feelings about their new breasts, sensed changes in their sexuality and attractiveness, and with whom they feel comfortable in disclosing that they had chosen to undergo a prophylactic mastectomy. In the post genetic testing era, the women were pioneers and were not sure how others would react to them or even how they, themselves, felt about their changed bodies after their prophylactic mastectomies. The working title for this article is "Women on the FORCE archived message boards: Renegotiation of the self and disclosure after a prophylactic mastectomy". The topics of these messages include: genetic testing and telling relatives, feeling different, breasts (sensation, shape, feel, nipples), attractiveness and sexuality, clothing, telling children, co-workers, and friends, and coming to terms with the PM. This manuscript should be ready for submission in Winter 2007 and, as with other papers, is intended to provide guidance for anticipatory counseling concerning life after PM, in addition to advancing theory in this area..

Additionally, a poster summarizing the goals of the grant and its progress was presented at the June 2005 Department of Defense Era of Hope conference. Dr. Regina Kenen also gave an invited talk entitled "FORCE as a Web Based Support Group and Information Source" to a Hereditary Breast/Ovarian Cancer Family support group at the Royal Marsden NHS Trust, October, 2005.

Findings to date suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community. These women face potentially life altering decisions concerning risk management strategies and struggle to balance risk reduction and quality of life.

The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. They experienced feelings of loss, as well as a changing sense of themselves as women during the adjustment to risk reducing prophylactic surgeries, and repeatedly expressed concern over the inadequacy of current research to address the issues most relevant to their health and quality of life. Specifically, studies that report the effects of HRT on menopausal women tend to focus on natural or surgical menopause in older women, but do not include younger high-risk women who have undergone surgical menopause for reduction of breast cancer risk. Nor do such studies explore the effects of alternate forms of HRT, including individualized bio-identical formulations. Controlled studies examining the impact of multiple forms of HRT on breast cancer risk in BRCA+ women following PO are warranted. Overall, there are substantial gaps in the preparation of these women for the experiences associated with decision making concerning risk management and the consequences of these decisions. Our goal is to produce results that both improve their preparation and strengthen subsequent support processes, particularly among women who do not have the benefit of the unique resources of F.O. R.C.E.

### **Key Research Accomplishments**

- Assembled investigator team
- Hired and trained research assistants
- Key personnel attended QSR-N-VIVO training
- Downloaded and converted entire FORCE archives HTML files to RTF format for use with QSR-N-VIVO, resulting in 5000 pages of searchable text documents
- Created a taxonomy of key issues warranting investigation based on frequency, volume, and duration of threads on the message boards
- Assembled FORCE consumer board for formal review and discussion of findings (member checking)
- Completed analyses of first topic: Decisions surrounding the use of HRT following PO
- Presented early results at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer*
- First manuscript has been submitted: “Peer-Support in Coping with Medical Uncertainty: Discussion of Oophorectomy and Hormone Replacement Therapy on a Web-Based Message Board,” to *Psycho-Oncology*.
- Analyses of second topic in progress: “Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board.” Decision to undergo prophylactic mastectomy with or without reconstruction, the

processes involved in such decisionmaking, and the impact of decisions on quality of life. Initial results were presented at the 2006 *Society of Behavioral Medicine* annual meeting.

- Analyses of third topic in progress: “The PM journey on the FORCE Website.” Prophylactic mastectomy and related issues, e.g., surveillance and reconstruction, influence of family history, genetic testing, pre-PM worries, pre-PM decisions, looking for help in making a decision, insurance coverage difficulties, deciding on surveillance instead of PM, day before PM thoughts and experiences, post-PM thoughts and experiences, trouble with implants, and giving information.
- Analyses of fourth topic in progress: Psycho-social interpretation of problems women face post-PM regarding risks of disclosure, possible stigma or rejection, sense of self and renegotiation of identity

### **Reportable Outcomes**

#### **Completed Presentations:**

Coyne, J.C., (September, 2005). *So genetic testing is not traumatic, now what?* Invited Lecture: Grand rounds, Department of Medical Genetics, University of St. Andrews School of Medicine.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (June, 2005). *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board*. Paper presented at the 9th International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer, Philadelphia.

Kenen, R. H. *FORCE as a Web Based Support Group and Information Source*. Presented at Hereditary Breast/Ovarian Cancer Family support group at the Royal Marsden NHS Trust, October, 2005.

Palmer, S. C, Shapiro, P. J., Friedman, S., Coyne, J. C. (June 2005). *Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer*. Poster presented at the Department of Defense Era of Hope Conference, Philadelphia.

Shapiro, P. J., Kenen, R. H., Hantsoo, L., & Coyne, J.C. (2005). *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*. Paper presented at the 2006 Society of Behavioral Medicine Annual Meeting.

#### **Work in Preparation or Under Review**

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (2005) Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board. Manuscript in preparation.

## **Conclusions**

This project is a unique collaboration between a multidisciplinary team of researchers and a non-profit organization of consumers that serves the needs of women and families affected by HBOC. Progress to date includes identification of key issues that affect both the immediate and long-term health and quality of life of women at genetic risk for breast and ovarian cancers. Detailed analyses integrating high-risk women's perspectives on these issues with the relevant medical and psychosocial literature are underway, with the first topic completed and three additional topics near completion. In addition, we have identified a number of topics for future analyses, including exploration of 1) women's psychosocial and pragmatic support needs during significant events such as receipt of genetic test results, cancer diagnosis, and cancer recurrence, 2) unmet healthcare needs, 3) and satisfaction with physician care.

General findings suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community as a means of coping with potentially life altering decisions concerning risk management. The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. In their struggle to balance risk reduction and quality of life, they repeatedly expressed frustration with the inadequacy of current research to address these issues. In addition to their individual concerns, women expressed concern for their children and future generations. This project gives voice to their concerns—a collective voice in their own words with the potential to shape future clinical, public policy, and research agendas for women and their families who live with inherited risk of cancer.

## **References**

None

## **Appendices**

*None*